Kidney Konnections

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The Bay Area Association of Kidney Patients is an all-volunteer, non-profit organization formed to educate and support Bay Area kidney patients.

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Bay Area Association of Kidney Patients

Stanford Transplant Team Outlines Kidney Post Transplant Care

By Marco Martin

At our January 10, 2010 meeting, over 90 attendees welcomed the Kidney Transplant Team from Stanford Medical Center to educate us about Kidney Post Transplant Care. Guest speakers Becky Fewster, RN, Post Transplant Coordinator; Donna Delgado, Patient Care Coordinator; and Patsy Obayashi, MS, RD, CDE, Registered Dietician and Certified Diabetes Educator were moderated by Dr. John Scandling, Stanford Professor of Medicine and Medical Director, Adult Kidney and Kidney/Pancreas Transplantation Programs. The meeting was lively with each speaker answering multiple questions from the audience.

Education about maintenance of the new kidney begins prior to hospital discharge. Remember, transplantation is not considered a cure and lifelong care is required to take care of your new kidney.

"The patient's dedication and motivation are the most critical components in the care of a new kidney," stated Ms. Fewster. The recipient is indeed a lucky person, as the need for new kidneys far outweighs the supply. The hospital stay is usually no longer

than a week and most patients go home in 3–5 days. The work disability period is usually 2–3 months for the kidney transplant recipient and, due to the new technique of laparoscopic kidney removal, only 3–4 weeks for a living donor. The recovery period may be longer for patients or donors that have more laborious jobs.

One of the things the patient learns about is the immunosuppressive drugs they must now take and the associated

Weight Gain and Post Transplant Diet

After your kidney transplant you can eat formerly forbidden foods such as bananas, cantaloupe, milk, and chocolate. Happy Day! But the immunosuppressive drugs can accelerate the addition of pounds – sometimes as much as 15-30 pounds. Calorie counting becomes essential! Transplant patients should try to stick to a "heart healthy" diet. Bake or broil your foods. Avoid animal



The Stanford Post Transplant Care Team

side effects. These drugs keep the immune system from rejecting the new kidney. Even a "perfect match" patient must take transplant medications daily. Ms. Delgado encouraged the use of a specialty pharmacy, thus alleviating the hassles of dealing with insurance companies. Patients are also taught the three main side effects of transplant medications: weight gain, hypertension, and diabetes.

fats; instead use plant oils. Saturated fat (fat solid at room temperature) will clog your system and reduce the circulation through your new kidney. Protein provides material for body building, but stick with lean cuts and non-fat milk. Eat whole grain breads, cereals, and pastas because they are high in fiber. Eat dark green, yellow and red vegetables the more colors, the more nutrients. Drink ample

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fluids, about 64-96 oz water/day, and exercise for 30 minutes five times a week. Do not skip meals and watch portion sizes. The overall goal here is to look and feel better.

Hypertension/Heart Disease

Hypertension (high blood pressure) and heart disease becomes an issue for men in their 50s and women in their 60s and occurs earlier in transplant recipients. Chronic kidney disease itself is a risk factor for heart disease. Hypertension can be controlled partially through exercise and diet (especially a low-salt diet).

Diabetes

Right after your transplant, blood sugar readings may increase in response to high doses of transplant medications (such as Prograf and Prednisone). In addition, as kidney function increases, the new kidney can filter out 1/3 of the insulin in your body; at a far better rate than prior to transplant. This calls for vigilant glucose monitoring in diabetics and can unmask any pre-existing diabetic conditions in others. Excess sugar makes the blood flow more slowly through the kidney, possibly leading to dehydration and sugar damage to kidney blood vessels. Diabetics' A1C reading should be below 7%; this blood test measures the average blood sugar readings over a three month period. Other lab goals are maintaining your LDL at less than 100, HDL at more than 40 for men, 50 for women. An ideal BMI (Body Mass Index) is < 25 kg/m². Diabetes educators, like dietitians, can help you achieve these goals through weekly programs. Ms. Obayashi also noted that Stanford has several free programs to help you. https://stanfordhospital.org/clinicsmedServices/COE/transplant/diabetes/

Rejection and Kidney Survival

Acute rejection is reversible when caught early; it usually occurs in the first six months post transplant. Late rejection (after one year post transplant) is not common and is most likely caused by non-adherence to medications. Dr. Scandling noted that there are no real signs of rejection; it usually is first detected through regular laboratory tests. Rarely, if there are symptoms, they could be fever, blood, and pain. Rejection can go unnoticed because, after the first six months, follow up blood tests are less frequent. Adherence to regular lab work is VERY critical, even if the patient is feeling well. Dr. Scandling also noted that Stanford has a 98% one-year survival rate of transplanted kidneys and that the website http://www.ustransplants.org publishes the success rates of kidney transplants at different U.S. centers.

After one year, a patient is not on as many medicines but should still avoid contact with sick people and wash their hands regularly as their immune system will always be somewhat suppressed. Diligent hygiene helps to avoid infections. However, Dr. Scandling commented that many transplant recipients notice they fare better than their family members in resisting infections, such as the flu.

The majority of transplants come from deceased donors. Statistics show that a deceased donor kidney is expected to last about 10 years, a living donor kidney about 20 years, and a kidney from a full matching sibling can give 30 years!

The goal of transplantation is to return you to full activity; you have received a wonderful gift. Enjoy!

Other Local Kidney Support Groups & Meetings

Patient Support Group

Open to all pre-dialysis, dialysis, pre-transplant, and transplant patients, friends, and family

Meets at 1 pm the second Saturday of every odd month at:
Kaiser Permanente-Santa Clara
Hospital Building, 700
Lawrence Expressway, Santa
Clara, CA

Contact: Lorraine Maloon, LCSW 408-851-1044

T.R.I.O Transplant Recipients International Organization

Silicon Valley Chapter Meets on the 2nd Thursday of each month at 7:30 pm. El Camino Hospital, Conference Room E, 2500 Grant Road, Mountain View, CA 94040

> www.bayareatrio.org 408-353-2169

San Francisco Polycystic Kidney Foundation

For general PKD information, call: 1-800-PKDCURE

For information about local groups, go to:

www.pkdcure.org/ sanfranciscochapter

For chapter specific questions, please send email to: sanfranciscochapter@pkdcure.org The National Kidney Foundation of No. California & No. Nevada

Has many resources available and sponsors many events.
For more info:

www.kidneynca.org 415-543-3303

National Kidney Foundation

www.kidney.org

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BAAKP Announces New Partnership

The Bay Area Association of Kidney Patients is proud to announce, as of January 2010, our partnership with Inquiring Systems Inc, a non-profit 501(c)(3) startup incubator in Sonoma, California as our Fiscal Sponsor. The long term goal of BAAKP is to become an independent 501(c)(3) organization, and our partnership with Inquiring Systems Inc will help us towards that goal.

This newsletter is not intended to be a substitute for advice from your medical professionals. Please consult your physician or other medical professionals about any changes or additions you make to your kidney care.

Check Out the Updated BAAKP.org Web Site!

Thanks to Ben Lee the BAAKP.org web site was recently updated. In addition to back copies of our newsletters there are links to videos from past presentations. New additions include a page with resource links and a page where you can make a tax deductible donation.



Attendees at a recent BAAKP educational meeting.

Thank You to Our Supporters!

The BAAKP is grateful to the <u>Stanford Adult Kidney Transplant Program</u> (<u>transplant.stanfordhospital.com</u>) for volunteering their Sunday afternoon to enlighten us. Special thanks to <u>Genzyme</u> Pharmaceuticals, which continues to provide \$250 to support each meeting. We are also thankful to <u>Willows Market</u> for donating the speaker's gift. In addition, the <u>Palo Alto Medical Foundation</u> holds a special place in our hearts for providing the fabulous meeting room and their continuing support. Without the efforts of these community members, our programs would not be possible.

A Letter From Our President

Each year thousands of people in the Bay Area are diagnosed with Chronic Kidney Disease. The goal of BAAKP is to educate and support those patients and their families as they learn to manage their health.

The BAAKP provides a wide range of services to help CKD patients become advocates on their own behalf. These include:

- Free quarterly educational presentations.
- Free quarterly informational newsletters.
- A free website containing videos and newsletters (<u>www.BAAKP.org</u>)
- A library of free literature and pamphlets at every meeting
- Free member advocacy and support.

All of this "freeness" does have a cost, though. It is mostly paid for by the hard work, diligence, and time that is donated to the BAAKP by the members of the BAAKP Steering Committee. Thousands of hours each year are invested to make sure that presentations and newsletters are both timely, relevant, and of the highest quality possible.

While the BAAKP is an all volunteer organization, we still need to cover the costs associated with the production of the presentations, the newsletters (printing and mailing), and hopefully, the eventual expansion of our capabilities.

This is where our request comes in. We ask that, if you find our work to be of benefit to you or those you know, to please make a tax-deductible donation to ISI and indicate BAAKP on the Remarks line of the check.

Donations can be made by:

- Returning a check in the envelope provided with this newsletter
- Donating at our meetings
- Donating online at <u>www.BAAKP.org</u>. Click on "Donate Now" and you will be linked to our donation page.

The members of the BAAKP Steering Committee are encouraged by the tremendous support that we have received over the past 3 years and look forward to expanding our services to help manage your health. We can only continue to do this with your help. Please donate!

Thank you,

Grant Bennett, President Bay Area Association of Kidney Patients

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Educating and Supporting Bay Area Kidney Patients

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Email: bay.area.kidney@gmail.com

Please visit our website at <u>www.BAAKP.org</u>
for back issues of our newsletters and videos of our past meetings!

Newsletter publication dates are November, February, May and August If you've received an extra copy of this newsletter, please pass it along!

SAVE THESE DATES! General Meetings:

- May 23, 2010
 Understanding Your
 Lab Results with
 Dr. Brian Carrie
- October 3, 2010
 Dr. Toby Gottheiner on
 Blood Pressure & Kidney
 Disease & the BAAKP
 Birthday Party!
- January 9, 2011
 UCSF Transplant Team with Dr. Tomlanovich

Steering Committee Meetings Second Wednesday of every month at 6:00 pm

If you would like to join us in the leadership of this group, we would love to have your help. (Call for location)

bay.area.kidney@gmail.com 650-323-2225

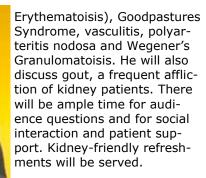
March 14, 2010 Meeting to Feature Mark Genovese, MD Discussing Autoimmune Disorders and Kidney Disease

The Spring meeting of the Bay Area Association of Kidney Patients will feature speaker Mark Genovese, M.D., Professor of Medicine and Co-Chief of the Division of Immunology and Rheumatology at Stanford University Medical Center.

All are invited to learn the many facets of autoimmune diseases, diag-

nosis, and treatment. Immunological diseases can involve the kidneys with some leading to Chronic Kidney Disease and eventual renal (kidney) replacement measures.

Dr. Genovese will discuss autoimmune disorders such as IgA nephropathy, lupus nephritis, SLE (systemic lupus



This free event will take place at the Palo Alto Medical Foundation, 795 El Camino Real, 3rd floor Conference Room, Palo Alto, CA 94301 on Sunday March 14, 2010 from 1 PM to 4 PM. To reserve your seat, please email us at bay.area.kidney@gmail.com or call us at 650-323-2225. You may also fax your reservation to 650-327-0178 or mail to BAAKP, Box 2332, Menlo Park, CA 94026.